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Hülür, Gizem ; Wolf, Henrike ; Riese, Florian ; Theill, Nathan

Abstract: BACKGROUND: Research on terminal decline has widely documented that cognitive performance steeply declines with nearing death. To date, it is unclear whether these changes are normative, based on pathologies associated with (preclinical) dementia, or both. OBJECTIVES: We analyzed heterogeneity in trajectories of terminal cognitive change in Swiss nursing home residents with the objective of examining whether terminal change is normative or whether one or multiple subgroup(s) with relative stability exist. METHODS: We performed a longitudinal analysis based on routine assessments with the Resident Assessment Instrument - Minimal Data Set in 341 nursing homes between 1998 and 2014. In sum, we used 143,052 observations from 30,054 residents (69% women, average age at death 87 years) in the last 3 years of life. We analyzed trajectories of the Cognitive Performance Scale (CPS) score with latent class growth curve models and examined sociodemographic factors (age at death, sex, marital status, prior living situation) as well as functional and mental health (Activities of Daily Living Index and Depression Rating Scale) and dementia diagnosis as correlates of group membership. RESULTS: We identified three distinct classes based on longitudinal trajectories of the CPS score. In the first group (transition from no to mild impairment, 27%), cognitive impairment increased with time to death (linear and quadratic), but remained at relatively mild levels at all times. The trajectories of the second group (transition from moderate to severe impairment, 43%) were characterized by linear and quadratic changes across time to death. The trajectories of the third group (severe impairment, 30%) were characterized by the lowest amount of linear increase across all groups and no quadratic increase indicating no accelerated change. Better functional health and absence of a dementia diagnosis predicted less impairment. Fewer depressive symptoms were associated with low as opposed to moderate or severe, but also severe versus moderate impairment. CONCLUSION: Our findings suggest that the majority of residents experience terminal change, with the exception of those at already high levels of impairment. Furthermore, late-life cognitive change is related to functional and mental health.

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Keywords
Terminal decline · Cognitive Performance Scale · Latent class growth curve analysis · Longitudinal

Abstract
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Introduction

Research on late-life cognitive functioning documented steep deteriorations at the end of life, a phenomenon that has been called "terminal decline" [1–5]. In the preterminal phases of late adulthood, cognitive change is characterized by relative stability or modest decline. In the terminal phase, where mortality-related processes set in, the rate of cognitive decline is much faster [6–8]. The mechanism underlying terminal decline of cognitive functioning is not clear. It has been argued that terminal changes in cognition at the end of life may reflect a general deterioration of the biological system [7, 9, 10]. On the other hand, evidence exists to suggest that terminal decline of cognition may be specific to individuals diagnosed with dementia [11–13].

Laukka et al. [11] examined trajectories of cognitive change in 1,200 participants of the Kungsholmen Project, a community-based sample of individuals at least 75 years old and free of dementia at baseline and residing in the Kungsholmen parish of Stockholm, Sweden. Longitudinal assessments of global cognition measured with the Mini-Mental State Examination (MMSE) [14] were obtained over 11 years at 3-year intervals. After excluding data from participants with incident dementia, i.e., those who developed dementia during the course of the study, they found no evidence for accelerated terminal decline of global cognitive performance. In another study using data from 585 participants of the Kungsholmen project, Laukka et al. [12] found that after excluding data from participants with incident dementia, mortality-related effects on cognition were attenuated for performance in tests of primary memory, episodic memory, verbal ability, and visuospatial ability. Nevertheless, cognitively healthy participants who died during longitudinal follow-up showed more decline in cognitive performance than cognitively healthy participants who stayed alive. Similar findings were reported by Piccinin et al. [13], who used up to five longitudinal observations at 2-year intervals from 461 participants of the Origins of Variance in the Old-Old Study (OCTO-Twin) to study trajectories of terminal cognitive change in cognitively healthy participants and in participants with incident dementia. They observed that cognitively healthy participants showed less pronounced declines in proximity of death compared to participants with incident dementia in two cognitive tests measuring general knowledge and visuospatial ability. Taken together, these findings suggest that terminal cognitive decline may be absent or much weaker in individuals free of dementia. In contrast, Thorvaldsson et al. [15] showed evidence for terminal decline in verbal ability, spatial ability, and perceptual speed in a sample of 288 participants of the Gerontological and Geriatric Population Studies in Göteborg, Sweden (H70) who did not fulfill the criteria for a dementia diagnosis until the end of their lives. It is important to note that although individuals with and without a dementia diagnosis may differ in trajectories of terminal cognitive change, the same mechanism may be responsible for these changes: neuropathologies related to dementia may also accumulate in healthy participants but remain below critical thresholds for a dementia diagnosis [16, 17].

In the present study, we examined cognitive change in close proximity of death in Swiss nursing home residents to investigate heterogeneity in trajectories of terminal decline. Previous studies focused on samples from the general older adult populations, and individuals with more severe health limitations may have been underrepresented. Also, data were collected at multi-year intervals, which may have made it difficult to focus on the last months of life, where mortality-related cognitive change may accelerate more rapidly. In the present study, we used data from the last 3 years of life of 30,054 nursing home residents (69% women, age at death mean = 87.49 years, SD = 7.00 years, range = 65–103 years). In recent years, a growing number of studies have examined questions related to the heterogeneity of late-life development with latent class growth analyses [18–21]. In latent class growth analyses, the goal is to identify unobserved groups of individuals based on their longitudinal trajectories [22, 23]. These studies have added to previous research on cognitive aging, e.g., by showing that the trajectory of the largest latent class was characterized by no cognitive decline in a sample of community-dwelling older adults aged ≥65 years [19]. Furthermore, Burns et al. [18] focused on terminal decline in the domain of mental health and well-being and found that the most common latent classes were characterized by stability in the last years of life. In the present study, we examined heterogeneity in trajectories of terminal change in cognition with latent class growth analysis in nursing home residents. Furthermore, we examined sociodemographic characteristics as well as functional and mental health as predictors of latent class membership.

Methods

Participants and Procedure

We used the Resident Assessment Instrument – Minimal Data Set (RAI-MDS) V2.0 [24, 25] that was routinely collected from the residents of 341 Swiss nursing homes (of about 550 total nursing

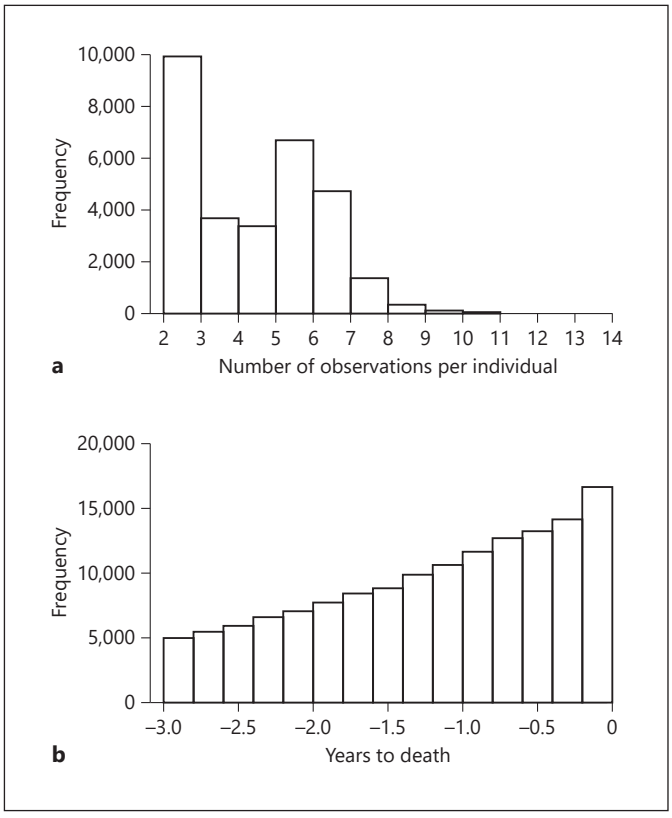

Fig. 1. Distribution of the available data points. **a** Distribution of number of observations available per individual. **b** Distribution of longitudinal observations across distance to death.

homes using the RAI-MDS) between the years 1998 and 2014. The RAI-MDS provides longitudinal data since an assessment is performed (a) upon admission to the nursing home, (b) every 6 months, and (c) upon significant change in care needs. In the present study, we used data from residents who died by 2014 and for whom the date of death was known and who provided data on the outcome variable and correlates. Focusing on terminal decline in old age, we selected observations between the ages of 65 and 100 years. Furthermore, since we were interested in analysis of change, we only used data from individuals for whom at least two observations were available. This resulted in 4.8 average longitudinal assessments per individual (SD = 1.96, range = 2–14). In total, we made use of 143,052 longitudinal observations from 30,054 residents. Figure 1 shows the distribution of number of observations per participant (Fig. 1a) as well as the distribution of longitudinal observations across time to death (Fig. 1b).

Measures: Outcome Variable

The Cognitive Performance Scale (CPS) score [26] of the RAI-MDS indicated the degree of cognitive impairment rated by caregivers and ranged from 0 to 6 (0 = intact, 1 = borderline intact, 2 = mild impairment, 3 = moderate impairment, 4 = moderate/severe impairment, 5 = severe impairment, 6 = very severe impairment). The CPS score is based on the RAI-MDS items indicating being comatose (yes/no), impairment in decision making, impairment in expressive communication, impairment in short-term memory, and independence in eating. CPS scores are highly correlated with MMSE scores [26–28].

Measures: Time Metric

Mortality status and an individual's year of death were obtained from the records of the nursing home. Time to death at each time point was calculated as the difference between the respective date and an individual's date of death in number of days and scaled in years, ranging from –3 to 0, and centered at 6 months prior to death.

Measures: Correlates

Sex was a binary variable (0 = men, 1 = women). Sixty-nine percent of the residents were women. Age at death indicated the difference between an individual's date of death and date of birth (mean = 87.49 years, SD = 7.00 years, range = 65–103 years). Residents' dementia diagnosis was represented by a binary variable indicating whether a participant was diagnosed with Alzheimer's disease or other dementias by a physician (1 = dementia diagnosis, 0 = no diagnosis). Thirty-five percent of the residents were not diagnosed with Alzheimer's disease or other dementias. To examine individual differences in depressiveness, we used the highest score of an individual on the Depression Rating Scale [29] across all available observations. In the Depression Rating Scale, caregivers rate the presence of mood symptoms, with scores ranging from 0 (indicating no mood symptoms) to 14 (indicating all symptoms present) (mean = 3.66, SD = 2.93, range = 0–14). Individual differences in functional health were captured by an individual's highest available score across all observations on the Activities of Daily Living Index of the RAI-MDS, with higher scores indicating higher dependency in activities of daily living (mean = 13.47, SD = 4.34, range = 4–18). Marital status was a binary variable (1 = married, 0 = other). Twenty-four percent of the residents were married at the first available measurement occasion. Residents' prior living situation was characterized by two binary variables indicating whether an individual was living in a private household (1 = yes, 0 = no) and whether an individual was living with others in a private household (1 = yes, 0 = no). Ninety-four percent of the residents had previously lived in a private household and 37% had previously lived in a private household with others.

Statistical Procedures: Growth Curve of the CPS Score

In a first step, we examined whether the treatment of the CPS score as continuous or categorical was more appropriate. We estimated a multilevel growth curve model [30] with a linear slope indicating change per year across time to death and a quadratic slope indicating accelerated change. At the within-person level, the model was defined as:

$$CPS_{it} = x_{0i} + x_{si}(\text{time to death}_{it}) + x_{sqi}(\text{time to death}^2_{it}) + e_{it} \quad (1)$$

CPS_{it}, the outcome variable, was repeatedly measured across time to death up to 36 months before death. x_{0i} is an individual-specific parameter representing the level of CPS score at the centering point (i.e., 6 months before death). x_{si} is an individual-specific parameter representing linear change in CPS score per year as an individual gets closer to death. x_{sqi} is an individual-specific parameter representing accelerated change in CPS score per year of death. Higher CPS scores indicate more cognitive impairment.

Table 1. Comparison of model fit across latent class growth models with increasing numbers of classes

Parameter	c = 1	c = 2	c = 3	c = 4	c = 5	c = 6	c = 7	c = 8
AIC	515,071	438,723	401,625	388,607	379,986	376,059	372,706	370,190
ΔAIC		76,348	37,098	13,018	8,621	3,927	3,353	2,516
BIC	515,150	438,842	401,784	388,804	380,223	376,335	373,022	370,546
ΔBIC		76,308	37,058	12,980	8,581	3,888	3,313	2,476
Entropy		0.895	0.896	0.876	0.888	0.858	0.825	0.826

AIC, Akaike information criterion; BIC, Bayesian information criterion.

Therefore, a linear slope >0 would indicate linear terminal increase in cognitive impairment, and a quadratic slope >0 would indicate accelerated increase. At the between-person level, individual-specific intercept and slope parameters were modeled as:

$$x_{0i} = \beta_0 + r_{0i} \quad (2)$$
$$x_{si} = \beta_s + r_{si} \quad (3)$$
$$x_{sqi} = \beta_{sq} + r_{sqi} \quad (4)$$

β_0, β_s, and β_{sq} are sample-level averages for the intercept, linear change, and quadratic change, respectively. r_{0i}, r_{si}, and r_{sqi} represent individual-specific deviations from these averages and are assumed to be normally distributed, correlated with one another, and uncorrelated with the residual variance e_{it}. When treating the CPS score as a categorical variable, a continuous latent response variable (CPS^*_{it}) is assumed to be underlying the observed categorical variable CPS_{it} [22, 31]:

$$CPS_{it} = \begin{cases} 0 \text{ if } -\infty < CPS^*_{it} \leq \tau 1 \\ 1 \text{ if } \tau 1 < CPS^*_{it} \leq \tau 2 \\ \quad . \\ \quad . \\ \quad . \\ 6 \text{ if } \tau 6 < CPS^*_{it} \leq \infty . \end{cases} \quad (5)$$

$\tau 1$ to $\tau 6$ are thresholds for CPS^*_{it}, e.g., when CPS^*_{it} passes the threshold $\tau 1$, CPS_{it} takes the value of 1. For CPS^*_{it}, the growth model is set analogue to the continuous variable with a probit link. Models were estimated in MPlus version 8 [32] with maximum likelihood robust estimation.

Statistical Procedures: Latent Class Growth Model

We used latent class growth models [22, 23] to capture heterogeneity in late-life trajectories of cognitive impairment as indicated by the CPS scores. Latent class growth models allow the identification of unobserved subpopulations based on trajectories of change. In these models, the variances and covariances of the growth factors were set to 0. Thresholds of the categorical variable, $\tau 1$ to $\tau 6$, were fixed to equality across classes. The intercept was set to 0 in one class and estimated freely in other classes. The rates of linear and quadratic change, β_s, and β_{sq} were allowed to vary across classes. The models were estimated with increasing numbers of classes at the between-person level, ranging from 2 to 8. Model selection was performed based on model convergence, the Akaike information criterion (AIC) and the Bayesian information criterion (BIC) (lower values indicate better fit) [33], the entropy index (values >0.80 indicate that individuals can be classified with confidence) [33], and plausibility of the class solution. We did not rely on likelihood ratio tests because the difference between subsequent models may become reliably different from 0 due to the extremely large sample size, although the improvement in fit may be small. In a next step, correlates centered at sample means were added to the model as predictors of group membership.

Results

The findings of the growth curve analysis indicated better model fit when the CPS score was treated as a categorical instead of a continuous variable (categorical model: AIC = 365,417, BIC = 365,555; continuous model: AIC = 410,645, BIC = 410,743). Thus, the CPS score was treated as a categorical variable in all analyses. Growth curve analyses with the full sample revealed evidence for terminal decline, with linear (β_s = 1.324, SE = 0.016, $p < 0.001$) and quadratic (β_{sq} = 0.291, SE = 0.007, $p < 0.001$) increases for the latent response variable underlying the categorical CPS score. In a follow-up analysis to study heterogeneity in terminal change of the CPS score, we extracted factor scores from this model. The findings suggested that most participants experience (accelerated) increases in impairment: for the linear change component, only 7% of individuals had a factor score of ≤0 indicating less impairment over time to death or stability. The CPS scores were higher among individuals with relative stability of the linear component, indicating more impairment. Among individuals with a factor score ≤0 for the linear change component, 50% of all longitudinal observations of the CPS score were 5 or 6, indicating severe impairment. Among individuals with a factor score >0, the percentage of CPS scores of 5 and 6 was

Table 2. Trajectories of cognitive change in three groups identified via latent class growth modelling

Parameter	Group 1 (27%): transition low to moderate impairment		Group 2 (43%): transition moderate to severe impairment		Group 3 (30%): severe impairment	
	estimate	SE	estimate	SE	estimate	SE
Means						
Intercept			2.341*	0.016	4.345*	0.022
Linear slope	0.866*	0.022	0.971*	0.016	0.343*	0.016
Quadratic slope	0.272*	0.010	0.220*	0.008	–0.014	0.008
Thresholds						
CPS 0–1	–0.574*	0.028				
CPS 1–2	0.287*	0.039				
CPS 2–3	1.104*	0.039				
CPS 3–4	2.715*	0.034				
CPS 4–5	3.211*	0.033				
CPS 5–6	4.939*	0.028				

Unstandardized estimates and standard errors are presented. Time to death was centered at 6 months prior to death. Higher values of the CPS indicate more cognitive impairment; therefore, positive values of the linear and quadratic slope components reflect linear and quadratic terminal increase in cognitive impairment with increasing proximity to death. CPS, Cognitive Performance Scale.
* $p < 0.001$.

27%. Seventy-six percent of the individuals had linear and quadratic slopes >0, indicating accelerated increase in cognitive impairment. Taken together, these observations suggest that the majority of individuals experienced terminal change, with the exception of those at already higher levels of impairment. Similar findings were obtained in a model with only a linear change component (5% of the individuals had a factor score ≤0 for linear change) and a model that treated the CPS score as a continuous variable.

Next, we examined which class solution was the most appropriate for the available data. The findings are presented in Table 1. The results revealed that the most appropriate characterization of growth trajectories was performed by a latent class model with three classes. First, we observed that AIC and BIC became smaller with each increase in number of classes; however, after the three-class solution, the decline in AIC and BIC was comparably small. Second, although entropy was satisfactory for all the class solutions examined, it was highest for the three-class solution. Finally, the three-class solution was more interpretable with respect to the identified classes. In a follow-up analysis, we created five random subsets of our data by randomly assigning each individual to one of five groups and repeated our analyses to examine whether the mixture solution would be confirmed. Analyses with all five data sets revealed the same pattern.

The model parameters and estimated trajectories from the three-class solution are shown in Table 2 and Figure 2, respectively. Higher values on the CPS measure indicate more cognitive impairment. Therefore, positive values for the linear and quadratic slope indicate (accelerated) terminal increase in cognitive impairment. The three groups were characterized by different trajectories of terminal change, as indicated by intercepts (distribution of the CPS scores over categories 6 months before death) as well as linear and quadratic slopes. Based on the most likely group membership for each individual, 27% of the sample belonged to the "transition from no to mild impairment" group, 43% belonged to the "transition from moderate to severe impairment" group, and 30% belonged to the "severe impairment" group. The linear and quadratic slopes indicated that the shape of estimated change differed by group: the CPS score indicating cognitive impairment showed linear and quadratic increases over time for the transitioning groups (no to mild impairment: $\beta_s = 0.866$, SE = 0.022, $p < 0.001$, and $\beta_{sq} = 0.272$, SE = 0.010, $p < 0.001$; mild to moderate impairment: $\beta_s = 0.971$, SE = 0.016, $p < 0.001$, and $\beta_{sq} = 0.220$, SE = 0.008, $p < 0.001$, respectively). For the severe impairment group, the CPS score was comparably stable and only evidenced a linear and no quadratic increase ($\beta_s = 0.343$, SE = 0.016, $p < 0.001$, and $\beta_{sq} = -0.014$, SE = 0.008, $p = 0.076$, respectively). The patterns of terminal change

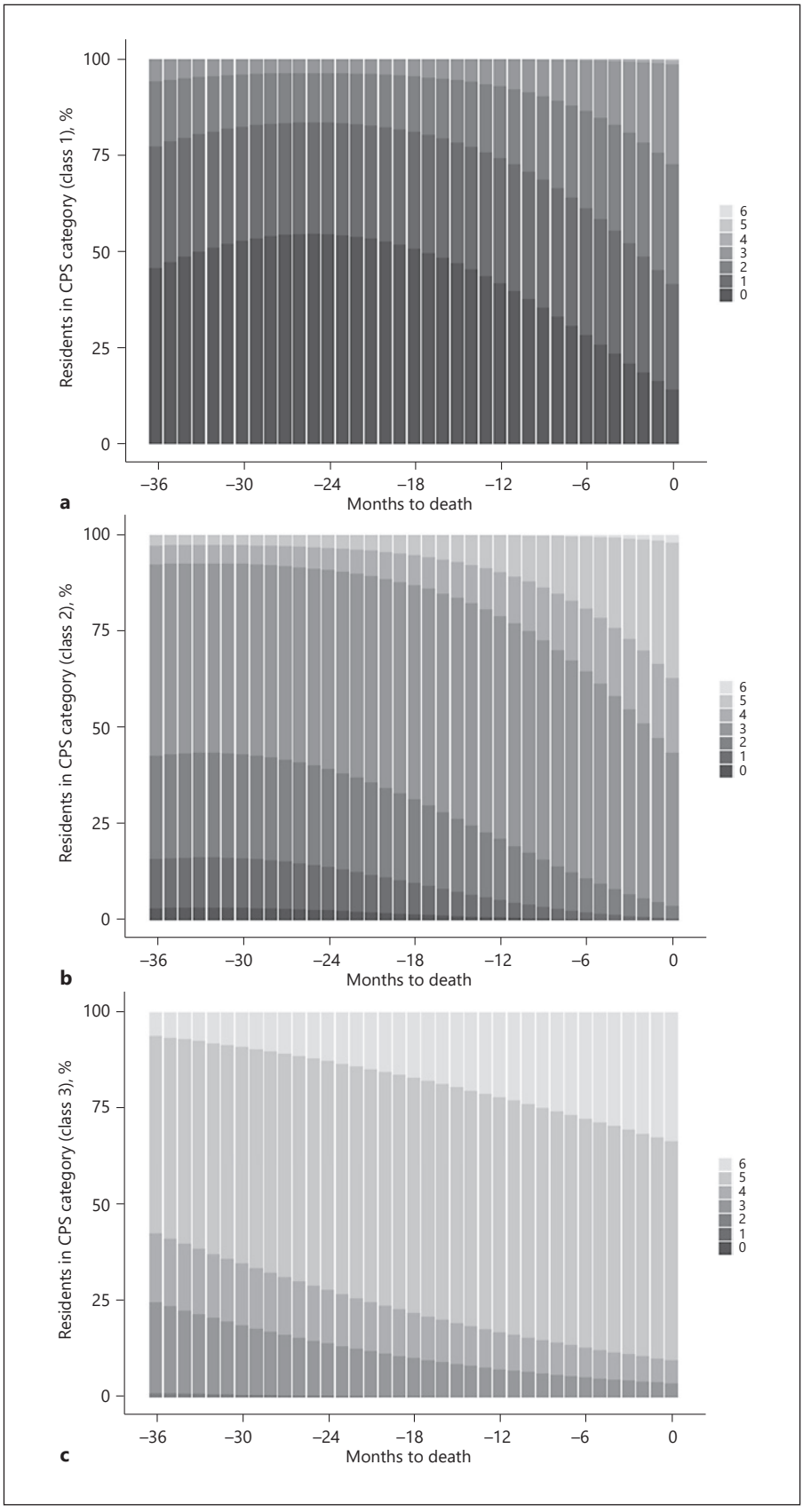

Fig. 2. Differences in terminal cognitive changes in three groups identified via latent class growth modelling. Higher CPS scores indicate more cognitive impairment. **a** Transition from no to mild impairment. **b** Transition from moderate to severe impairment. **c** Severe impairment. CPS, Cognitive Performance Scale.

Table 3. Predictors of membership in three groups identified via latent class growth modelling

Parameter	Group 2 vs. 1: moderate vs. low impairment		Group 3 vs. 1: severe vs. low impairment		Group 3 vs. 2: severe vs. moderate impairment	
	estimate	SE	estimate	SE	estimate	SE
Intercept	1.065*	0.048	–0.064	0.073	–1.129*	0.042
Age at death	0.020*	0.003	0.003	0.003	–0.017*	0.003
Sex (1 = women, 0 = men)	–0.214*	0.042	0.075	0.054	0.289*	0.042
Dementia diagnosis (1 = yes, 0 = no)	2.231*	0.039	3.397*	0.058	1.166*	0.049
Functional limitations	0.153*	0.004	0.484*	0.010	0.332*	0.010
Depression rating	0.111*	0.007	0.061*	0.009	–0.050*	0.006
Marital status (1 = married, 0 = other)	–0.088	0.055	–0.036	0.064	0.052	0.048
Lived in private household (1 = yes, 0 = no)	–0.281*	0.081	–0.918*	0.093	–0.637*	0.068
Lived with others (1 = yes, 0 = no)	0.306*	0.046	0.761*	0.055	0.454*	0.041

Unstandardized estimates and standard errors are presented. Correlates were centered at sample means. Time to death was centered at 6 months prior to death. Higher values of the CPS indicate more cognitive impairment; therefore, positive values of the linear and quadratic slope components reflect linear and quadratic terminal increase in cognitive impairment with increasing proximity to death. CPS, Cognitive Performance Scale. * $p < 0.001$.

are illustrated in Figure 2. In the "transition from no to mild impairment" group, terminal change was characterized by linear and quadratic decline in the proportion of category 0, and linear and quadratic increases in the proportion of categories 2 and 3. In the "transition from moderate to severe impairment" group, there was linear and quadratic terminal decline in the proportion of categories 1, 2, and 3 and linear and quadratic terminal increase in the proportion of categories 4 and 5. In the "severe impairment" group, there was a linear increase in the proportion of category 6 and a decline in the proportion of categories 3 and 4.

Table 3 shows the predictors of group membership by correlates. These findings are also illustrated in Figure 3. Because ORs >1 are more intuitive to interpret, we reversed the independent variables to produce ORs >1 (e.g., Fig. 3a shows the ORs for men, whereas Figs. 3b and c show the ORs for women). For continuous variables (age at death, functional limitations, depressive symptoms), we calculated the OR associated with 1 SD lower or higher levels than the sample mean. Having more functional limitations and being diagnosed with dementia consistently predicted belonging to a group with higher impairment (OR ranging from 1.94 to 8.16 for 1 SD higher functional limitations, and OR ranging from 3.21 to 29.87 for having a dementia diagnosis, respectively; Fig. 3). A higher depression rating was also associated with belonging to the "transition from moderate to severe impairment" group (OR = 1.38 for 1 SD higher depressive symptoms) or the "severe impairment" group (OR = 1.20 for 1 SD higher depressive symptoms) as opposed to the "transition from mild to moderate impairment" group. However, it was also associated with belonging to the "transition from moderate to severe impairment" group as opposed to the "severe impairment" group (OR = 1.16 for 1 SD higher depressive symptoms). The same pattern of findings was also observed for a higher age at death; however, as can be seen in Figure 3, the effects of age at death were rather small in magnitude (OR <1.15). Men were more likely to be in the moderate versus low impairment group (OR = 1.24) and women were more likely to be in the severe versus moderate impairment group (OR = 1.34). There were no sex differences in belonging to the severe versus low impairment group. Not living in a private household prior to entering the nursing home (OR ranging from 1.32 to 2.50) and living in a private household with others (OR ranging from 1.36 to 2.14) were associated with belonging to groups with higher impairment. Marital status was unrelated to the probability of group membership (OR ≤1.09).

Discussion

Using routinely collected data from >30,000 Swiss nursing home residents, we examined heterogeneity in trajectories of terminal change in cognition. Higher values in our outcome variable, the CPS score, indicate more

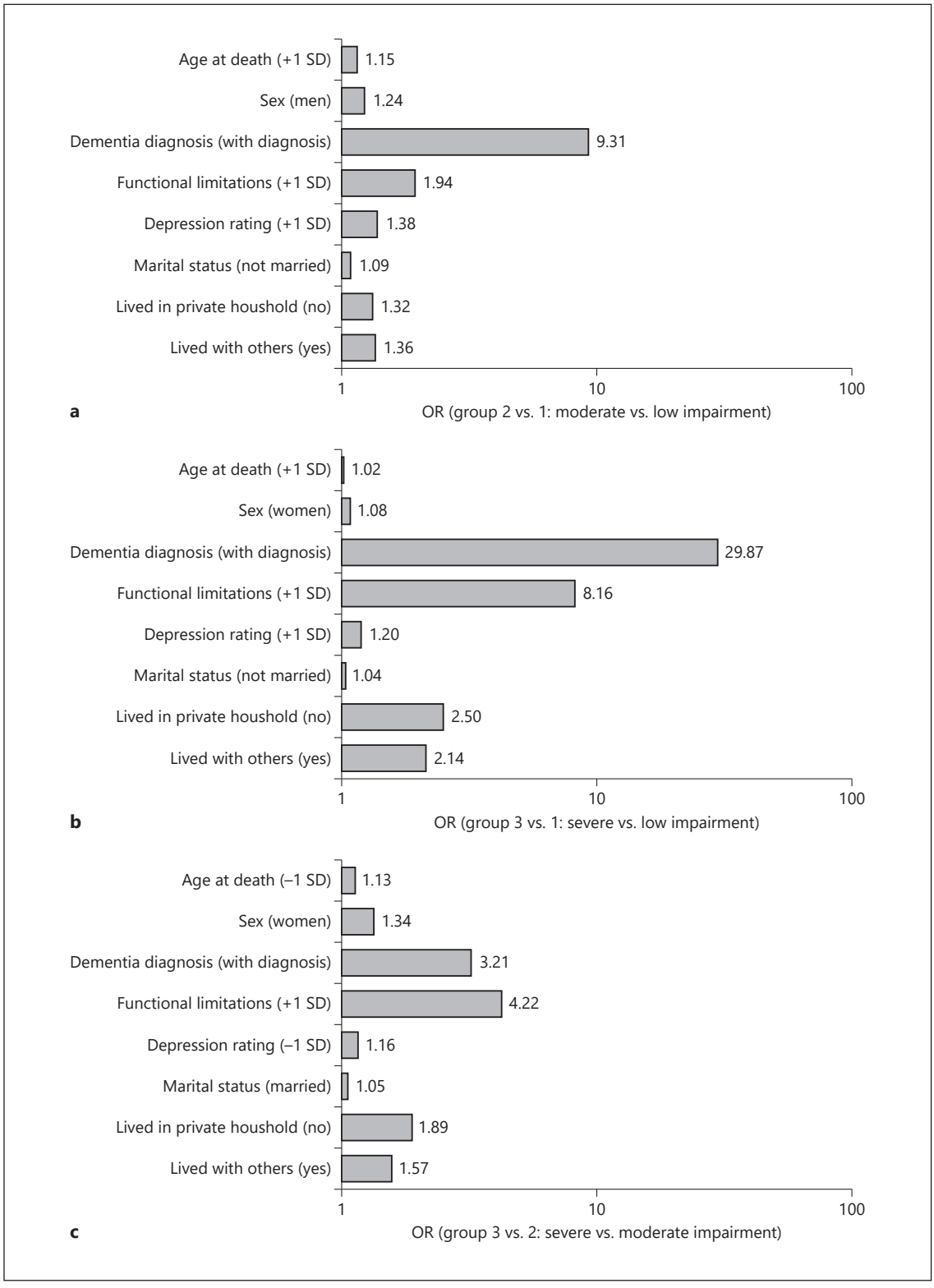

Fig. 3. Predictors of membership in three groups identified with latent class growth modelling. **a** Moderate versus low impairment. **b** Severe versus low impairment. **c** Severe versus moderate impairment.

cognitive impairment. In line with previous research showing terminal deteriorations of cognitive function at the end of life, we found evidence for accelerated terminal increase in cognitive impairment at the sample level. Furthermore, we observed terminal change in cognition in all latent classes identified via latent class growth analyses. However, there were differences in the shape of change between groups. Participants at already higher levels of impairment showed comparably less increase in impairment and no accelerated increase with approaching death. These participants may have experienced accelerated cognitive change at a previous time point. Groups transitioning from no to mild and from moderate to severe impairment both experienced considerable linear and quadratic cognitive change across time to death. Our findings extend previous research by focusing on terminal change in cognition in a vulnerable population that may have been underrepresented in previous studies. Previous studies relied on data from the general older adult population with relatively wide annual or multi-year time intervals between assessments. Our findings showed that even in a more vulnerable sample with health limitations, differences in terminal decline trajectories existed. As can be expected, our study showed comparably less evidence for stability of cognition before death than previous studies focusing on general older adult populations.

Various individual difference factors predicted the shape of cognitive change at the end of life. Having better functional health and no dementia diagnosis were consistently associated with membership in groups with lower impairment. The association between functional health and cognitive trajectories at the end of life suggests that terminal decline of cognition is related to functioning in different domains [34]. In addition to functional health, mental health, as indicated by the number of mood symptoms rated by caregivers, also predicted cognitive trajectories at the end of life. Residents with higher depression ratings were more likely to belong to the moderate or severe impairment group as opposed to the low impairment group. This finding suggests that terminal change in cognition is associated with well-being and mental health at the end of life [35]. However, the residents with the higher depression ratings were also more likely to belong to the moderate as opposed to the severe impairment group. Residents who lived independently before entering the nursing home had lower probability of belonging to groups with higher impairment.

According to the cognitive reserve hypothesis [36, 37], individuals with higher cognitive reserve capacity should enter the terminal phase at a later time point, but show stronger decline once terminal processes set in [7]. A number of recent studies examined whether participants differed in trajectories of terminal decline depending on their cognitive reserve capacity [6, 38–40]. Our observation that participants with lower levels of initial impairment show stronger decline may be interpreted as supporting this hypothesis. Unfortunately, we do not have more information about cognitive reserve prior to entering nursing home, e.g., about the educational level of the residents. Future research should examine whether cognitive reserve serves as a protective factor even in a vulnerable population and life phase. Furthermore, previous research has shown that trajectories of terminal change for mental health and well-being are characterized by stability for most individuals [18]. It is an important question for future research whether nursing home residents can maintain mental health and well-being at the end of life despite cognitive decline.

Our goal in this study was to examine heterogeneity in terminal cognitive change in nursing home residents, and we considered latent class growth curve models the most appropriate approach for our purposes. One alternative would have been to classify individuals based on dementia status (e.g., no dementia diagnosis throughout the observation period, incident dementia, and dementia diagnosis from the beginning). Although our study includes relatively frequent measures of the CPS score, dementia status is typically not as frequently assessed in nursing homes, leading to a considerable diagnostic gap [41–43]. Thus, even if a person is not diagnosed with dementia until their death, we will not know with certainty that they were indeed free of dementia symptoms. Another alternative is to determine the level of impairment based on categories of the CPS and analyze trajectories of change separately for groups differing, e.g., in initial levels of impairment. However, it is not clear what the optimal thresholds for the CPS score are [44], and such a decision is always somewhat arbitrary. Therefore, we chose the more data-driven latent class approach as the most appropriate to examine heterogeneity in terminal cognitive change in the nursing home setting. One important limitation of the latent class approach is that the number of identified classes may reflect floor or ceiling effects in available data [45]. The CPS and MMSE scores may lack appropriate sensitivity at lower levels of impairment to detect subtle changes [46, 47], a limitation that has been discussed in previous research on heterogeneity in terminal decline [11]. That we were nevertheless able to observe terminal change in individuals with relatively low levels of impairment shows that floor effects were not particularly severe in the present study. In

contrast, the finding that participants with severe cognitive impairment showed considerably less increase may imply the existence of ceiling effects. However, a high CPS score already reflects a very high level of impairment, and it is unlikely that an individual can experience even higher levels of impairment. Therefore, the observed ceiling may not be related to the scale but to the nature of the observed phenomenon [48].

Conclusions

Taken together, our findings demonstrate that the majority of nursing home residents experience terminal cognitive change, with the exception of those who already show high levels of cognitive impairment. Furthermore, our findings show that terminal change in cognition is related to functional and mental health.

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Statement of Ethics

Since the analysis was based on anonymous routine care data, no approval by the local ethics committee was required (cantonal ethics committee Zurich declaration of no objection 103-2015, KEK-ZH-Nr. 2012-0102).

Disclosure Statement

The authors have no disclosures to report.

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